

2007 Utah Cancer Survivorship Summit Evaluation Results?

Summit Objectives

1. Provide cancer survivors with information and education
2. Increase awareness of cancer resources in Utah
3. Give cancer survivors a chance to network with fellow survivors/sense of community
4. Survivors leave with a sense of hope and inspiration

Results from scale questions.

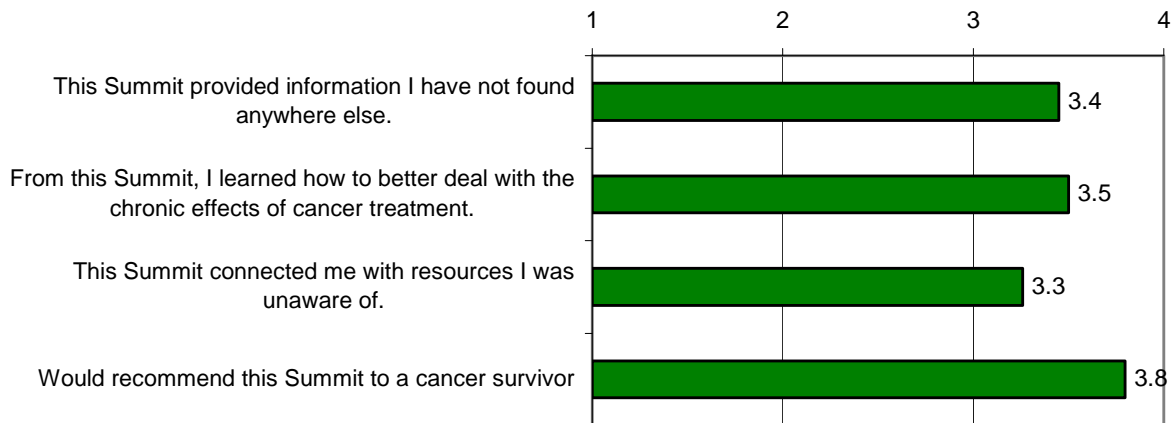
1 = Strongly Disagree

2 = Disagree

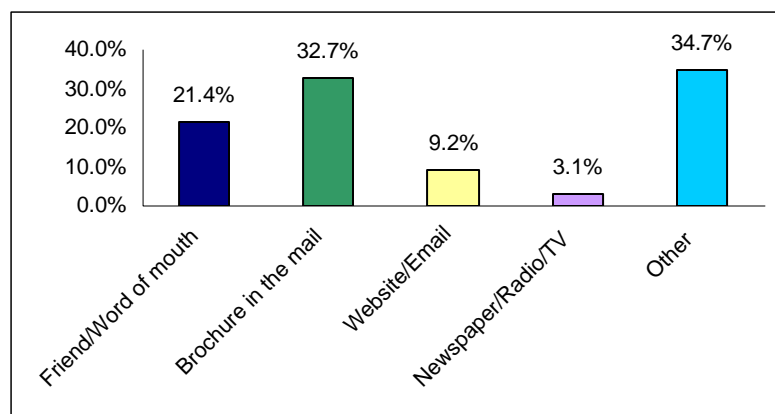
3 = Agree

4 = Strongly Agree

98 respondents



How did Survivors hear about the Summit?



What type of cancer were they most interested in?

Advanced prostate is my main concern	1.02%
All	5.10%
All forms	1.02%
All w/ relapse (CNS)	1.02%
All, testicular	1.02%
Bladder, breast, skin	1.02%
Brain Tumor - pediatric	1.02%
breast	13.27%
breast and metastatic illness	1.02%
breast and oral	1.02%
breast and prostate	1.02%
breast cancer	3.06%
breast cancer and the other places it spreads to	1.02%
breast/hodgkins lymphoma/skin	1.02%
Burkitts lymphoma	3.06%
Cervical	2.04%
clear cell carcinoma	1.02%
colon - skin - breast	1.02%
colorectal	1.02%
Endometrial Adenocarcinoma	1.02%
Leiomyosarcoma in uterus	1.02%
leukemia	1.02%
lung	1.02%
lymphoma	2.04%
Meddulloblastoma	1.02%
Medulloblastoma/brain tumors	1.02%
melanoma and colon	1.02%
Mult. Myeloma	1.02%
Multiple Myeloma	1.02%
neuroblastoma	1.02%
no specific	1.02%
ovarian	2.04%
Pediatric brain tumor	1.02%
prostate for husband	1.02%
Radiation Poisoning	1.02%
skin	1.02%
There is a lot out there about breast	1.02%
uterine	1.02%
Unknown	37.76%

Other

ACS Volunteer	3.2%
Brochure at hospital	3.2%
Brochure at Huntsman Center	3.2%
Brochure at IHC medical center	3.2%
Brochure picked up at	
Huntsman	3.2%
Candlelighters	6.5%
Cassia Regional Paper Stories	3.2%
Central Utah Clinic	3.2%
Daughter	6.5%
Dr. Eyring	3.2%
Huntsman	3.2%
Huntsman Cancer Center	3.2%
IHC Newsletter	3.2%
Intermountain Healthcare stories	3.2%
Magazine	3.2%
Magazine in Dr. Office	6.5%
My mom	3.2%
My wife's support group	6.5%
Navitas	6.5%
Support group	3.2%
Support group -Utah Central Clinic	3.2%
UCAN	3.2%
UCAN Member	3.2%
Was asked to moderate panel	3.2%
Wife	3.2%
Workgroup member	3.2%

What could be done differently next year? (Responses from Summit evaluation)

- Better lighting - couldn't see presentations very well
- More info about nutrition and attitude
- A comprehensive, large list of resources (not 20 different handouts).
- A workshop for co-survivors (caregivers)
- Advertise more - We happened to find out about it in a magazine at a Dr's Office. Panelist intros too long!! - more question time!
- Advertise more, more time at booths, panel stories too long - good but long
- Better advertised
- Better advertised, more involvement
- Better speakers
- Better way of curing cancers
- Big signs at Huntsman Cancer telling about the summit
- Broaden invitation list. More care providers.
- Clearer screen, could not see words and photos - all was blurry - larger photos.
- Confirm receiving my registration
- Don't know - was my first year attending - probably could be expanded to 3:00 pm - we drove 3 hours to get here.
- Fruit in the morning - fewer carbs. Exercise session
- Get more people here.
- Great program! Where to go for best doctors with best history of success w/ patients; treatment centers with least amount of negative outcomes. More concise answers from panel - more time for panel. Thanks for a great day!
- Have more teen activities
- Help in finding support locally for specific types of cancer.
- How about small group sessions by cancer type - I'd like to meet and talk to other prostate cancer survivors. Also, strong focus on wellness and positive attitude
- I did not have childhood cancer, but I am interested in the long-term effects of cancer and treatment. Could this be presented in the adult cancer track?
- I had a hard time understanding all the "vocabulary" and terms used. I wish some of the speakers would have spoken in more "layman's terms."
- I really enjoyed both speakers. The panel was good too. It helps to hear other's stories and know I'm not alone.
- Improved advertisement. I know that there are many people who could benefit who weren't here.
- Information on a Gamma Machine/Surgery
- Invite different representative from support groups and parent support groups.
- It serves a great cause and should be better advertised. There is a huge contingency in Ogden and (cannot read word) who weren't informed. Better system for feed-back/survivor's panel.
- It was good this year.
- It was great! I wouldn't change it.
- It was very hard to see the screen because of outside light.
- Keep schedule a little tighter.
- Less speakers or more time for speakers. Start on time. Maybe serve lunch while the survivor panel talks.

- Make slides easier to see.
- More educational help
- More help and ideas for caregivers.
- More of the same
- More speakers and gynecological specialists.
It would be awesome if I could get some of you to come and speak in Burley, Idaho.
There are no groups there.
- More variety of speakers
- Name tags for attendees. That's all I could think of. Really great speakers! Fantastic handouts!!
- Not have the presenters in front of a window - very hard to see them.
- Not much. I should mention Dr. Miller lost me with his technical terms at times. Also add a health insurance rep.
- Nothing really
- Provide translation to encourage Hispanic participants.
- Public advertising
- Question/Answer with doctors - would have like to ask Dr. Miller about some more things. Group discussions.
- Reach out to all survivors in Utah or SL Valley (Wasatch Front)
- Same
- Start on time.
- Start on time?
- Survivor's Panel - should have had enforced time limits, though all were interesting. Ian's comment on the bag on the belly should have been challenged; an ostomy is better than the alternate
- Tags or buttons that cancer survivors could wear so they could interact and share and learn
- The survivor panel
- Time for questions for doctors and presenters. Small group discussion groups
- To extend the time! Have the panelist after lunch. Q & A period.
- Too much medical that was too technical. Hard to understand and relate to.
- Very good job!
- W/A

What is the most valuable part of this summit? (Responses from Summit evaluation)

- Activities for the kids - My kids had a blast! Thank you!
- Advertise this! I found it "by accident" on the UCAN website, but would not have heard of it otherwise.
- All of it - presentations were very good!
- All of it. Thanks for a great program!
- All of the friends you meet who can relate to you.
- All of the positive attitudes!
- All speakers and panelists were outstanding - Thank you.
- All the resources you learn about.
- All the speakers have been very informative and positive. Dr. Miller's presentation was very useful. I go to Navitas for support group and rehabilitation.
Really like the panel.
- All the speakers were great. I really like Jeff Warren and the Survivor Panel and Greg

Miller, MD.

- Being a part of such a wonderful and unique group of people
- Being with other survivors
Hearing good information
- Being with others who are celebrating.
- Cognitive late-effect remedies
- Connecting patients with resources in the community - letting them know they are not alone
- Doctor's presentation and survivor panel
- Dr. Miller's info ab fatigue
Jeff Warren's frank style of talking
- Dr. Warren - cancer related fatigue
- Emotional support.
- Exercise is the answer to survival
- Exercise once again is the key.
Getting people together - Greater awareness.
- Fun to see people we know
- Good information
- Great Panel!!!
Resources available for long term effects and overall information.
- Handling fatigue with exercise
Treatment for prostate cancer - significant improvement and emphasis on quality of life
- Hearing about others who survive
- Hope, Strength in observing my daughter's cancer and how to listen a talk to her.
- I am happy to hear other survivors' and caregiver's stories.
I was extremely impressed with the medical professional's talks.
- I loved all the speakers
- I loved each speaker in adult track.
- I loved this summit!! Thank you for the medical docs who explained certain aspects of our cancer.
- Info
- Information and encouragement. I really liked the fatigue information. Thank you.
I like the location. I never would have wandered here by myself and it is a lovely building and grounds.
- Information and finding others with the same cancer.
- Information on fatigue and the feeling of hope.
- Information! Information! Information!
- It was all very inspirational and motivating!
- It was great - the inspiration of it - cancer is a bummer, but life is good
The variety of speakers was good.
- Jeff Warren / Panel
- Jeff Warren's presentation.
- Jeff Warren's Talk
- Just listening to the speakers
- Late effects childhood speaker
Thank you. It exceeded my expectations.

- Learning about long term effects
Learning about pain
- Mingling with others with similar situations
- More knowledge about late effects and how to recognize and what to do to screen for them (thanks!)
Also good info on who to see for chronic pain.
- My attitude about cancer and treatments is paramount and to pass it on.
- New procedures and treatments available
- Panel
- Panel
- Panel discussion/presentation
Dr. Peter Fisher
- Personal stories and sharing experiences about finding meaning in one's life while living with cancer
- Peter Fisher's talk on where treatment and diagnosis is headed in the future.
Everyone was very informative and helpful.
- Post surgery effects and healing (physical - environmental)
- Real people real stories
- Resource of health link for late effects
- Seeing and hearing from cancer survivors.
- Seeing others and hearing their stories
- Speakers - Doctors with their current information and especially the survivor's panel gave us hope to keep going.
- Speakers and information that was given out.
- Speakers and panel were great
It is perceived that cancer is an old person's disease. It's nice to see/hear stories and meet those who are younger.
- Speakers, panel, etc.
- Speaking with other people.
- Support
- Survivor's Panel - but every element was worthwhile.
- Than you all for all you have provided us.
- That it is focused on survivor education.
- That their will be better stuff for the future!
- The aftereffects of treatments and resources
- The optimism and hope
- The panel - hearing how others have dealt with school, cognitive, and other problems
- The positive message we can make a difference/Empowering, can change life for better!
Information sources
Ideas on history of tx and pain management
Sharing experiences with other patients
- The RN who spoke about late effects was very informative.
The opening - hearing from people who survived.
The panel discussion.
- The show of hope
- The speakers
- The speakers did a great job educating us and the panel members gave us hope

- The stories from the survivors.
- The Survivor's Panel
- togetherness
- We need a support group and rehab center in our area
- Your Life

What are your unmet needs? (Responses from registration question)

- Dr.'s and staff who understand the survivorship issues.
- Public awareness of colorectal cancer. While I got Governor Huntsman to declare March as Colorectal Cancer Awareness Month, the only public awareness out there about this disease is what U-CAN is generating. We need to get the Governor in 2008 to really step up his support publicly about Colorectal Cancer as you are well aware is the nations second leading cancer killer. I would like to film this event and need your support to film interviews for my documentary. Thank you
- I ended up with a permanent colostomy. It would be great to find others who have had this type of cancer and had a colostomy to see if they have any insights. I go to the support group at Navitas and to the physical therapy program at Nativitas. This has been so wonderful. Navitas has been the answer to so many questions about what happens when you are done with treatment. Just being finished with treatment and learning how to get on with life is one big need.
- After effects of Chemo, tamoxefin, and hot flashes coming off meds.
- I have no unmet needs. The people I have met have been great. There are many opportunities out there I just need to avail myself of them.
- How to deal with some ongoing side effects from medication for metastatic cancer-hand foot syndrome, infections that don't go away with standard treatments, unable to exercise (walk) due to foot tenderness
- The lack of information for re-occurrence treatment.
- Emotional support and validation (from other than my medical caregivers).I expected to be facing cancer totally alone--but during six months of treatment, friends, neighbors and co-workers were very supportive and encouraging. With the completion of successful treatment, however, my support system" virtually disappeared! As a "5-year Survivor I still have fears and concerns for my future--but no one with whom to share them.
- Not enough information on handling fatigue
- Not enough information on handling fatigue
- My insurance is fighting me on not paying for my wigs. They don't think they are necessary. I beg to differ. I'm also having a hard time finding a medical bracelet indicating no blood pressure or needles on my left arm.
- Because I relapsed in 1999 at the age of 12 and spent much of the next 4-5 years in treatment and for the most part out of school, I feel like I missed some very important social skills. As a 20-year-old, I find myself feeling out of place in social settings and I'm unsure of skills needed to maintain long-term relationships. There is a lot of emphasis on late-effects, but I think the social psychological impact is a late effect that needs to be addressed more.
- Getting support after you have lost a loved one
- Lack of medical check ups for long term survivors who have had more then on diagnosis of cancer. Also the lack dealing with long term side effects of treatments. Finally the lack of dealing with the emotional needs of long time survival.
- How to manage follow up care and communicating with Drs.

- What to do to regain my strength after treatments end? There needs to be a plan, ideas, and some direction given so you know how to get your life back. The doctor visits/follow up continues, but how do you get your life back?
- Understanding what now having a diagnosis of cancer implies with future insurance coverage. As well, as any genetic testing getting tagged to your name for the rest of your life to prevent insurance coverage.
- Learning to deal with the anonymity of ongoing maintenance check-ups, labs.
- Social Work intern, working with cancer patients and affected by cancer with the loss of my mother 4 years ago.
- I am not a survivor but a volunteer and RFL Team Development Chair. My brother is a 6-year survivor (Hawai'i) of colon cancer, but 13 people in my family, including my husband's mother, have not survived. I just attended the ACS summit last weekend. I want to learn as much as I can about UCAN and the resources and services available here in Utah.
- I have been very fortunate with all four of mine and haven't really had any unmet needs. I had my first one when I was 9. Had cervical and uterine and then a basil cell on my upper lip area in 99. Thank you for this summit and making the public more aware that there are avenues of support for all with cancer out there.
- I don't know if you ever get over the fear of recurrence.
- I would have liked to see more follow-up support after surgery etc. Especially during the first few months.
- Information and treatment on recurrences.
- Quality of life issues for extended survivorship have started to receive some exposure, but need more.
- Pain, shortness of breath, body weakness
- Insurance has been a problem; my health has been good except for these biggies. I've been involved with support groups for breast cancer and ostomy patients (had a colectomy in 2002)
- I need a comprehensive recovery plan, and recovery support. I need quality information on recovery that could have helped my employer understand and support me. I need cognitive rehab therapy to help me deal with \"chemo brain.\" I need occupational therapy to help me regain my fine motor and daily life skills after neuropathy. I need more information on how and where a variety of symptoms connected to my cancer and cancer treatment. Sorting out cancer/treatment/unrelated health issues has been very difficult. I need information on what after-effects of cancer are permanent vs. what can be cured or improved. I need my insurance to pay more of my recovery costs.
- Needed info on after-effects of radiation and how to overcome the fatigue. Needed info on how is my weight gain related to my cancer and treatment, and what to do about it. Needed info on my rights as a state employee to accommodations on the job during and after treatment.
- Too few support groups -- only one regular prostate cancer group, that meets only once a month. considering how many are diagnosed every year, only a very few have access to support and education groups
- a state or local support group for prostate cancer diagnosis and survivors
- Finding proper pain management, finding doctors who are willing to fight my case as hard as I am and having the insurance companies do their jobs instead of me having to do it for them...
- Dedicated support channels such as 800 phone numbers and/or groups of similar survivors.

- Nutrition and Natural Health care
- The need to talk with other multiple myeloma survivors.
- support and continued treatment